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ABSTRACT

This study used a focus group approach to examine the transition planning experiences and concerns of 30 family members of young adults with special health care needs throughout Massachusetts. Findings indicated: (1) parents experienced challenges with service delivery systems, day-to-day living, residential location, and uncertainty about the future; (2) parents struggled with the challenges of day-to-day living, including the management of responsibilities and obligations as well as the provision of daily specialized care; (3) parents described challenges associated with residential location, including poor transportation, greater isolation, and difficulty accessing resources; and (4) parents were challenged by the future uncertainty of adult supports and resources and were concerned about what might happen after they are no longer able to care for their son or daughter. Results suggested recommendations concerning improved access to information, establishment of longitudinal supports, and the need for flexible resources. (DB)

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Introduction

Adolescence is a time of rapid change for young people and their families. This period brings a negotiation of relationships and roles, changing life routines, and a mixture of fear and excitement about new opportunities. Adolescents with special health care needs and their families are no exception to these changes; yet they also face additional challenges. Planning for long-term health care, medical insurance, and day-to-day support needs may bring family members more closely into the transition process as the adolescent strives for independence. Parents' legitimate fears about safety and security may lead them to remain engaged in their children's lives. Finally, families and young adults must negotiate a variety of new service systems and rules during this period.

This study examined the transition planning experiences and concerns of family members of young adults with special health care needs throughout Massachusetts. As a planning activity of the Department of Public Health's Massachusetts Initiative for Youth with Disabilities (MIYD), this study investigated the challenges that these families faced during the transition from school to adult life.

Methodology and Participants

This report summarizes the experiences of 30 family members throughout Massachusetts. Five focus groups were conducted across the state (see Table 1). Twenty three of the 30 family members were white, two were African-American, and five were Latino. Focus group participants included parents of young adults with chronic medical conditions, physical disabilities and developmental disabilities. Case studies were also conducted with three additional families that detailed their experiences as they prepared for their children's transitions from school to adult life. Table 2 describes the families profiled in the case studies.

Table 1
Focus Group Location and Participation

Location	# of Participants
West Boylston*	1
Newton	7
Athol	12
Lakeville	6
New Bedford	4

* Since only one parent attended this focus group it was conducted more in the style of an interview.

Table 2
Case Study Families: Descriptive Information

Family	Location	Child's Gender	Child's Age	Disability
Family 1	Suburban Boston	Female	19	tubular myopathy
Family 2	North-Central Mass	Male	19	amino deficiency, asthma, dysmotility
		Female	12	GI complications, asthma
		Female	10	autism, epilepsy
		Female	7	chronic intestinal pseudo-obstruction
Family 3	Western Mass	Male	11	Down Syndrome

Findings

Parents experienced challenges with service delivery systems, day-to-day living, residential location, and uncertainty about the future.

Parents felt that service delivery systems were:

- Inconsistent: Parents found that effective service delivery is often dependent upon a specific situation or individual and that good service delivery often seems circumstantial and unpredictable.
- Difficult to negotiate: Parents described haphazardly wandering through systems, ultimately "falling into" or uncovering resources in an inefficient and coincidental manner.
- Lacking coordination, communication and joint action with schools: Parents recognized that their children's transition needs crossed both agency and school lines, yet they lacked confidence that schools and agencies accepted equal responsibility.
- Unresponsive: Parents characterized systems as unwilling and unable to accommodate their children's needs. They described schools as lacking resources, overburdened or not having the level of staffing support required to go beyond standard educational curriculum.

Parents struggled with the challenges of day-to-day living. This included the management of responsibilities and obligations as well as the provision of daily specialized care.

- Parents described themselves as their children's case managers- juggling multiple school-related meetings and medical appointments, coordinating with vendors for medical equipment and supplies, while keeping on top of the typical household chores.

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- Parents also described themselves as their children's highly specialized nurses- providing daily therapies, lifting, washing, dressing and draining of feeding tubes. Parents felt that this physically and emotionally challenging lifestyle virtually precluded any meaningful planning for their children's futures.

Parents described challenges associated with residential location including poor transportation, greater isolation and difficulty accessing resources.

- A lack of transportation resources was a problem for parents in rural areas whereas parents in urban areas noted unreliable transportation.
- Parents in rural areas reported difficulties linking up with formal services, informal networks and recreational and social opportunities for their children.
- Parents in rural and suburban areas noted that the specialized care required for their children does not exist in their communities. They commented on the difficulties of traveling long distances to meet their children's unique service needs.

Parents were challenged by the future uncertainty of adult supports and resources and were concerned about what might happen after they are no longer able or present to provide for their son or daughter.

- Parents sensed an abrupt end to the service delivery pathways created through the school when their child reaches the age of 22.
- Parents feared that siblings would have to take on responsibility for care in their absence.
- Because of this uncertainty, parents planned less regarding formal adult services and resources. However, parents spent more time improving skills acquisition, expanding the social and vocational capacities of their children, facilitating support networks and providing exposure to varied vocational and life experiences.

Implications and Recommendations

The findings of this study emphasize barriers to transition planning faced by parents of young adults with special health care needs as they prepare their children for adult life. The following recommendations are for policymakers and service professionals.

Improve Access to Information

- Support the development of broad based community resource guides that address both generic and disability-specific resources.
- Develop alternative ways to make information available, including the Internet and telephone-based information and referral.
- Invest in "community builders" or individuals who are knowledgeable about, or skilled in, developing community resources.
- Provide preservice and inservice training that emphasizes the skills of community development and community networking.
- Insure cross-agency information sharing.

Establish Consistent Longitudinal Supports

- Provide continuity in case management across children's and adult services. This will enhance the provision of a full spectrum of information about transition resources and avoid personnel changes at a time of significant stress for families.
- Explore policies and practices that afford families and individuals the ability to choose their sources of support, since family needs, cultures and styles vary.
- Invest in and support informal network building such as family-directed outreach projects or parent-to-parent networks.

Support Flexible Resources

- Expand the emphasis on self-directed service delivery. Flexible family support money allows individuals and families to efficiently target resources in order to meet their unique needs.
- Support alternative ways to access specialized resources such as local clinics, mobile resources such as van-based adaptive equipment services, telephone consultation options, and consultation networks for local medical professionals. New technologies for video and Internet conferencing can be considered to meet these needs in remote locations.
- Support local transition planning teams to develop and integrate resources across schools, adult and community-based agencies.

For more information on this study, please contact Jaimie Ciulla Timmons at (617) 355-8212, <ciulla_j@a1.tch.harvard.edu>

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